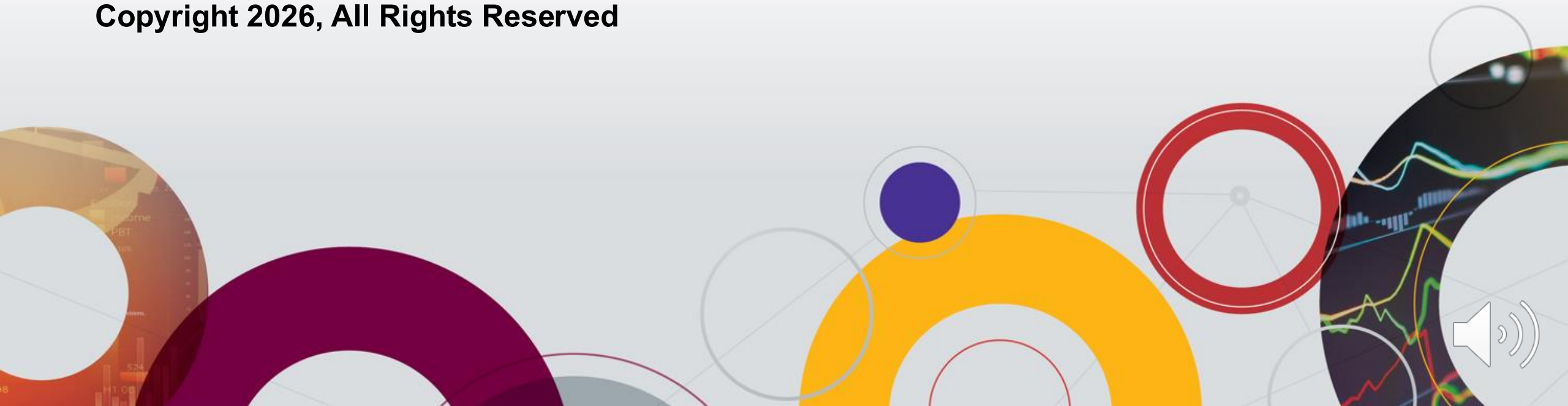


3.6 Personal Health Records

10x10 – Introduction to Biomedical Informatics & Artificial Intelligence
William Hersh, MD, FACMI, FAMIA, FIAHSI
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Personal health records

Definitions

Approaches and examples

Next steps

Personal health record (PHR) definitions

ASTP/ONC (2019) – “a record controlled by the individual and may include health information from a variety of sources, including multiple health care providers and the patients themselves. The PHR is separate from, and does not replace, the legal record of any health care provider.”

MedlinePlus (NLM, 2019) – links to many resources

PHR part of patient portal and guided by principles of consumer health informatics

PHR – key overviews

Shenkin (1973) (!)

Tang (2006)

AHIMA-AMIA (2007)

Reviews of functionality, efficacy, and challenges (Roehrs, 2017; Bouayad, 2017)

Benefits for stakeholders (AHIMA-AMIA, 2007)

Consumers, patients, and caregivers – support healthcare and wellness

Healthcare providers – improve care delivered

Payers – improve customer service

Employers – improve employee productivity

Society/population – strength health promotion and disease prevention

Types of PHRs (Tang, 2006)

Tethered

- Stored in healthcare provider's EHR
- Often allows communication with provider
- May allow patient to add information

Standalone

- Isolated application on individual computer – may use mobile device or Web site

Interconnected or integrated (Detmer, 2008; Tang, 2009)

- Separate application but integrated with provider EHR(s) for, e.g., test results, scheduling, data collection, etc.

Approaches and examples

Tethered

- Epic MyChart
- myHealtheVet

Standalone

- WebMD Health Manager

Integrated

- Apple Health

Tethered PHRs

Typical functions include

- Allow viewing of patient's data in EHR
- Patient able to communicate with healthcare provider for appointments, refills, and non-urgent questions
- Provide access to consumer-oriented library of health information
- Usually browser-based, but increasingly on mobile devices

Example: Epic MyChart

- Secure view into Epic EHR with additional patient-oriented functionality
- Available via Web and smartphone apps
- Provides access to all providers who use Epic
- Increasingly integrated with outside records

MyChart – computer

MyChart Bill Hersh Log Out

Mailbox Visits Medical Record Billing Resources My Account

Welcome!

No new notifications.

To Do

FERRITIN
Ordered by Joseph A Hardman, MD on Nov 27, 2018
Expected: Feb 27, 2019 (approximately)

NEW Consult with Anne C Trainor, FNP
Monday March 18, 2019
Arrive by 2:30 PM
Starts at 3:00 PM

Expires: Dec 27, 2019

March 2019

S M T W T F S

3 4 5 6 7 8 9

10 11 12 13 14 15 16

17 18 19 20 21 22 23

24 25 26 27 28 29 30

31

Quick Links

- View test results
- Ask a question
- Schedule an appointment
- Refill medications
- Review health summary
- View billing summary
- Start eVisit

Health Summary

Use the links to jump directly to a section of your Health Summary.

Current Health Issues Medications Allergies Immunizations

Please review your health issues, and verify that the list is up to date. Call 5

Dyslipidemia
Added 8/7/2009
[Learn more](#)

Essential hypertension
Added 8/7/2009
[Learn more](#)

Allergic rhinitis due to pollen
Added 5/17/2010
[Learn more](#)

Tubular adenoma of colon
Added 6/3/2013
[Learn more](#)

Cervical radiculopathy at C7
Added 11/21/2013
[Learn more](#)

Ischial bursitis of right side
Added 2/5/2015
[Learn more](#)

What's in My Record?

- Health Summary
- Test Results
- Medications
- Allergies
- Current Health Issues
- Immunizations
- Medical History
- Preventive Care
- Plan of Care

Medical Tools

- Download My Record
- Growth Charts
- Lucy/MyChart Central
- Request Records
- Health Trends
- Questionnaires
- Research Studies

EyeCare Center

Last Eyeglass Prescription

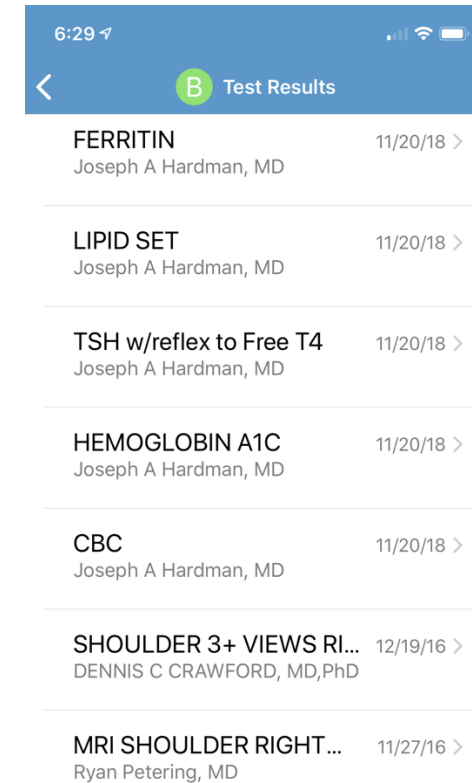
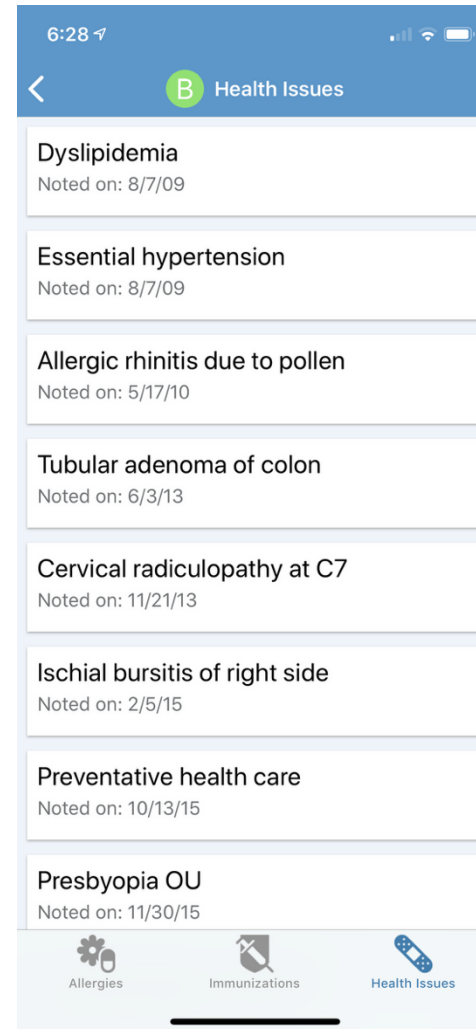
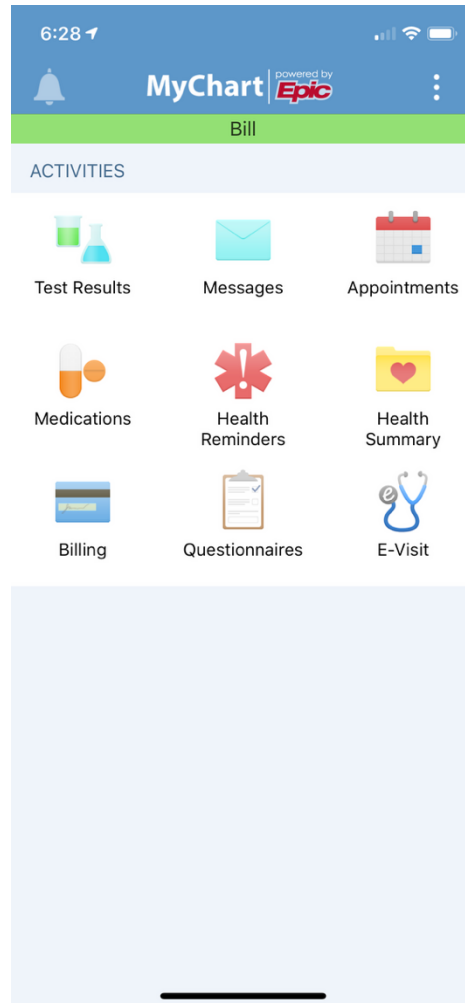
Test Results

Search this list ☐ Show Hospital Results

Test	Ordered By	Date
FERRITIN	Joseph A Hardman, MD	Nov 20, 2018
LIPID SET	Joseph A Hardman, MD	Nov 20, 2018
TSH w/reflex to Free T4	Joseph A Hardman, MD	Nov 20, 2018
HEMOGLOBIN A1C	Joseph A Hardman, MD	Nov 20, 2018
CBC	Joseph A Hardman, MD	Nov 20, 2018
SHOULDER 3+ VIEWS RIGHT	DENNIS C CRAWFORD, MD, PhD	Dec 19, 2016
MRI SHOULDER RIGHT WO CONTRAST	Ryan Petering, MD	Nov 27, 2016

Here you can see your lab results, along with the person who asked for the lab test to be done. Click a row to view more details.

MyChart – mobile



MyHealthVet – tethered to the VA system

The screenshot displays the MyHealthVet website interface. At the top, the VA logo and 'My healthvet' branding are on the left, while search, about, and contact links are on the right. A navigation bar below contains links for Home, Personal Information, Pharmacy, Get Care, Track Health, Research Health, and MHV Community. A central banner prompts users to 'Login to Manage Your Healthcare' with 'Login' and 'Register' buttons. The main content area features four service tiles: Pharmacy (refill prescriptions), Appointments (track upcoming visits), Messages (secure communication), and Health Records (view/print/download records). Each tile includes an icon, a title, a brief description, and a 'Read More' link. Below this is a 'Resources' section with links to Benefits, Veterans Health Library, Community, Mental Health, Healthy Living, and HealthLiving Assessment.

VA | My healthvet Search | About | Contact

Home ▾ Personal Information ▾ Pharmacy ▾ Get Care ▾ Track Health ▾ Research Health ▾ MHV Community ▾

Login to Manage Your Healthcare [Login](#) [Register](#)

Pharmacy

Refill your VA prescriptions, track delivery, view a list of your VA medications and other details.

[Read More](#)

Appointments

Keep track of your upcoming VA medical appointments and get email reminders.

[Read More](#)

Messages

Communicate securely online with your VA health care team and other VA staff about non-emergency information or questions.

[Read More](#)

Health Records

View, print, or download a copy of your VA medical record information, or enter your own health information.

[Read More](#)

Resources

[Benefits](#)

[Veterans Health Library](#)

[Community](#)

[Mental Health](#)

[Healthy Living](#)

[HealthLiving Assessment](#)

Standalone PHR – WebMD Health Manager



[WebMD Home](#) >

Care Providers



Sign in to access a patient's health records using a WebMD ID

[CLICK HERE TO SIGN IN](#)

Connected through your employer or health plan?

Sign in as instructed by your employer or health plan.



personal health record

Easy. Organized. Safe. FREE From WebMD

A single, secure location for your complete health information.

Ready to Begin?

Create my personal health record now.

[REGISTER](#)

Already Have One?

Existing WebMD Health Manager users sign in.

[SIGN IN](#)



Want more?

WebMD Health Manager contains your personal health record as well as health assessments, a personalized health plan and more. Get it all!

[Sign up now - it's FREE. No strings attached.](#)



What is a personal health record?

A personal health record permits you to securely gather, store, manage and share your own and your family's health information - when you want, where you want, and with whom you choose. And the WebMD Health Record is more than your personal health history. It's smart. It works within the WebMD Health Manager to provide you useful information and direct you to tools that you might find helpful.

Why should I create a personal health record?

- To easily gather, store and manage lifelong personal health information
- To share relevant information with authorized care providers
- To maximize your health benefits

At WebMD, we take the issue of privacy very seriously. WebMD is a recipient of the URAC e-Health Seal, a participant in the TRUSTe Privacy Program, and HON. You can be assured we will always put your privacy concerns first. Please read our [privacy policy](#) for more details or click on the seals below.

Integrated PHRs

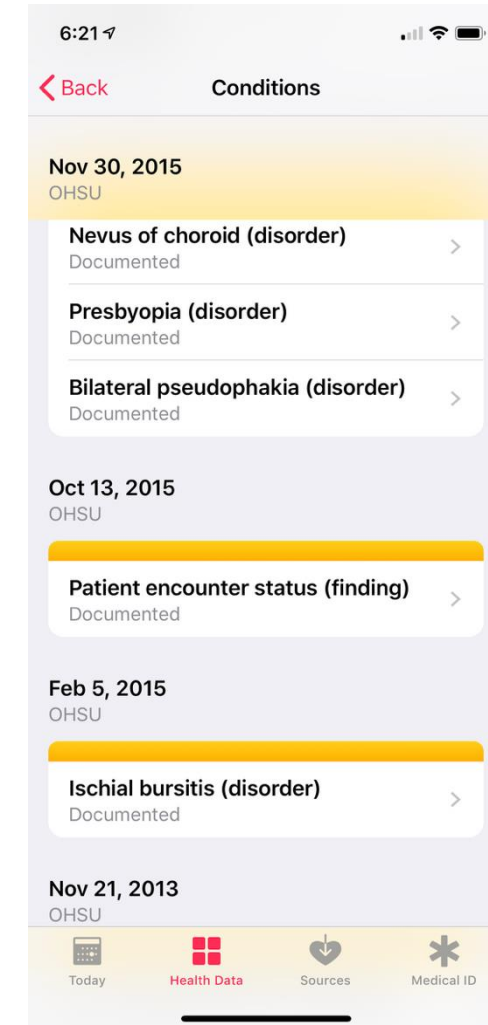
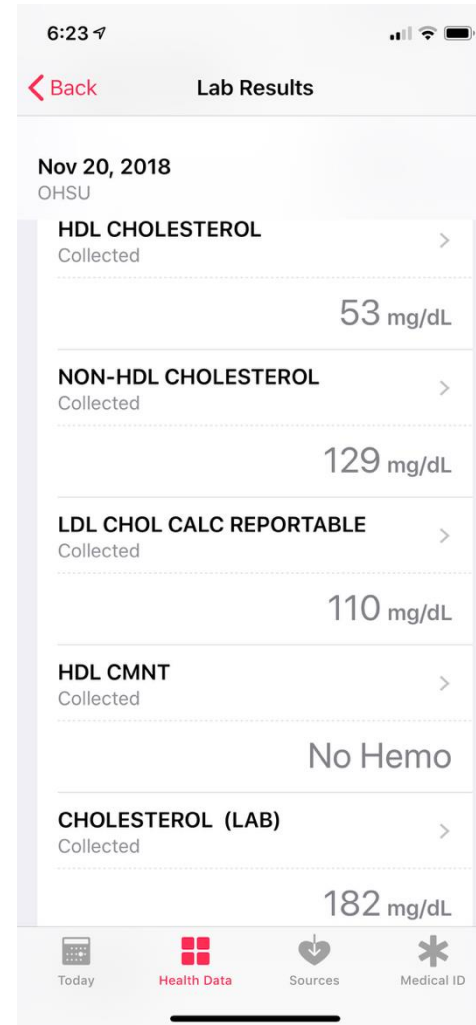
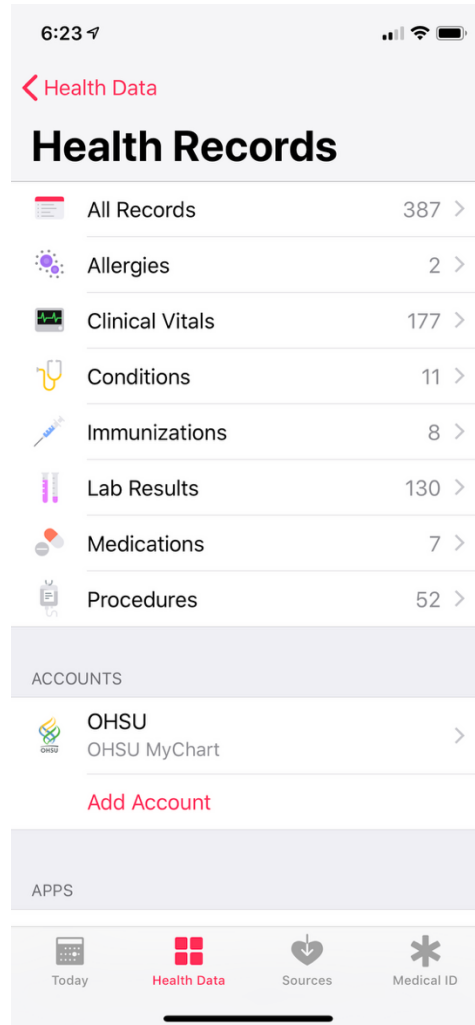
Some notable failures

- Google Health
- Microsoft HealthVault

Apple Health – integrates health from many mobile apps

- Devices – e.g., scales, blood pressure, fitness trackers
- Apps – e.g., fitness, health measurements
- EHR – Epic data (Mandl, 2018; Monica, 2018)
- In the smartphone era, the tipping point for PHR usage (Dameff, 2019)

Apple Health app



Immediate release of patient results

Required notification and availability (with results if patients request) under context of information blocking prohibitions of Cures Act (Blease, 2021)

Concerns about

- Patient (mis)understanding and distress (Giardina, 2018)
- Confidential content for adolescents (Bedgood, 2023)
- Release of cancer information before patient discussion (Anyidoho, 2023)

At Vanderbilt University Medical Center

- Increased viewing of results by patients before physicians from 10% to 40% (Steitz, 2021)
- Opt-in policy for returning results moderately reduced amount of viewing and patient-initiated messaging (Steitz, 2023)

Patient access to their clinical notes – OpenNotes

Allowing patients to read clinician notes via their PHR

About a decade of use, with strong uptake and mostly positive experience (Walker, 2019)

- Patients believe important part of care and rarely troubled by what they read

Reinforces importance of using clear and respectful language and being inclusive of patient (Klein, 2016; Lin, 2017; Luks, 2021; Lam, 2023)

- Including access to images and their interpretation (Ellenbogen, 2021)

Concern about digital divide (Sangal, 2021)

Toward more appropriate language in patient notes (Luks, 2021)

Improper term or phrase	Why the term or phrase is problematic	More appropriate language
Misused terms and neologisms		
Chest x-ray	An x-ray is a beam of energy that we cannot see	Chest radiograph
Room air	The inspired oxygen fraction is the same inside or outside of a room	Air or ambient air
The patient denies drug use	Denying something connotes that it is there, but the patient refuses to admit it	The patient reports no use of illicit drugs
The patient endorses pain	To endorse is to declare public approval or support of something; patients are unlikely to be in favor of pain	The patient reports pain
Transaminitis	The liver enzymes are not inflamed; the liver or muscle cells are injured	Elevated liver enzymes
Troponinemia or troponemia	Neologisms	Elevated troponin
Problematic phrases from patient- and family-centered care standpoint		
Big-gun antibiotics	Terms related to guns or violence should not be used with patients or colleagues	Broad-spectrum antibiotics
Mr/Mrs [surname] is our CHF'er	Patients are more than their medical problems; this usage runs the risk of altering team perspectives on the patient	Mr/Mrs [surname] is a person with heart failure
The patient is a poor historian	Historians gather and interpret information; the patient is the source of information but may not be able to provide data for many reasons	I had difficulty obtaining a full history because...
The patient is trying to die	Patients rarely come into the hospital with the intention of dying	The patient is very ill and at high risk of dying
Transfer to the floor	The floor is a surface on which we stand or put furniture; patients are transferred to a specific unit in the hospital	Transfer to the [name of unit]
We should circle the wagons and...	The phrase implies gathering in defense of a group and may have negative connotations for some patients	We should touch base with the [appropriate team] for help
We should pull the trigger and...	Terms related to guns or violence should not be used with patients or colleagues; resonates poorly with patients who have experienced gun violence	We should administer [insert medication]

Principles and strategies for patient-centered notes (Lam, 2023)

Patient-centered principle	Strategy
Engage patients and strengthen the patient-clinician relationship	1. Include a brief rationale for tests, referrals, and medications to promote engagement
	2. Recognize and empower patients as team members. Consider partnering language such as “We decided”
	3. Celebrate patient successes. Encourage future behavioral or self-management changes by using the word “yet”
Partner with patients to improve note accuracy	4. Create a shared visit agenda and document patient values and preferences to help patients see themselves in the note
	5. Encourage patient feedback on notes and respond compassionately to errors. Differentiate between inaccurate medical facts (that should be corrected) and clinical opinions. Agree to disagree when needed
	6. Less is more. Avoid copy/paste behaviors and the excessive use of templates, imported data, and jargon
	7. Avoid surprises in the note: “Discuss what you write and write what you discuss”
Respect patients by avoiding judgmental and stigmatizing language	8. Address sensitive topics respectfully. Describe rather than label
	9. Recognize and replace judgmental or stigmatizing language with neutral language to avoid transmission of bias through the medical record
Encourage patients to access and read notes	10. Encourage all patients to read their notes between visits, in concert with organizational health information equity efforts to improve access Note: Organizations can engage patient and family advisory committees to co-develop educational materials on what to expect from notes and how to help patients get the most out of notes. They can also support efforts to better understand and address engagement disparities

Initial research on OpenNotes

Initially implemented in three academic centers (Delbanco, 2010; Delbanco, 2012)

- Portal to access physician notes
- Accessed by 47-92% of patients who signed up
- 77-87% felt more in control of care
- 60-78% felt increased medication adherence
- 26-36% had privacy concerns
- 1-8% felt confusion, worry, or offense
- For most part, physicians did not perceive increased time outside of visits, report changing content, or require more time for writing notes
- Almost all patients and physicians continued using system after study ended

Patient perspective

- Developed serious illness; appreciated transparency and access to information (Meltsner, 2012)
- About one-third of patients had concerns about privacy before and after use, but these did not deter usage (Vodicka, 2013)
- 20% shared with others (Jackson, 2014)

Further research from OpenNotes

Implementation in VA system

- In one center, patients believed approach (Woods, 2013)
 - Improved communication with their providers
 - Enhanced knowledge of health and self-care
 - Allowed for greater participation in decision-making
 - Benefitted their care
- Across VA, similar positive acceptance (Nazi, 2015)

Also acceptance in other settings – Boston, MA (Bell, 2017)

- Improved relational benefits between patients and physicians
- Small number of errors found; quickly resolved

Simplicity and continuous access to notes associated with improved understanding of notes, although still high cognitive burden for most patients (Khasawneh, 2022)

Next steps – OurNotes (Walker, 2021)

Next step beyond reading of notes is patients contributing to them

Before scheduled primary care visits, patients submit word-constrained, unstructured interval history and agenda for what they would like to discuss at visit

Providers invited to incorporate submissions into notes documenting visits

Initially implemented in primary care clinics at four academic medical centers across US

Usage by 174 clinicians and 1964 patients found general high satisfaction and continued use after study period

Toward patient control of their data?

Growing view that patients are owners and stewards of their data; should everyone have cloud-based data store with access granted to patient-chosen providers? (Hersh, 2017)

- Implications for current vendor-centric data storage, integrity of data, and cost model
- Patients can annotate but not alter data from healthcare system

Requirements (Mikk, 2017)

- Standard data elements
- Standard receipt for all data
- Contract that sets rules for access and control

Physicians and healthcare organizations “subscribe” to their patients’ data (Choi, 2018)?